DOCUMENT RESUME

ED 465 236 EC 308 992

TITLE	Communication at Home and in the Community: Helpful Strategies & Suggestions from Parents & Families with a Child Who Is Deaf-Blind.
INSTITUTION	National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind, Monmouth, OR.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	1999-00-00
NOTE	20p.
CONTRACT	H025C60001
AVAILABLE FROM	NTAC, Western Oregon University, Teaching Research Division, 345 N. Monmouth Ave., Monmouth, OR 97361. Tel: 800-438-9376 (Toll Free); TTY: 800-854-7013 (Toll Free); Fax: 503-838-8150; e-mail: dblink@tr.wou.edu. For full text: http://www.tr.wou.edu/ntac/pdf/parent99.pdf.
PUB TYPE	Opinion Papers (120)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Children; *Communication Skills; *Community Involvement; *Deaf Blind; Family Role; *Interpersonal Communication; *Parent Attitudes; Parent Role

ABSTRACT

This brief booklet lists communication strategies identified at a 1999 national parent workshop by over 100 parents and family members of children with deaf-blindness called "Important Practices in Communication: Making It Happen at Home and in the Community." The booklet addresses four questions: (1) How can we facilitate and promote a child's individualized mode of communication? (2) How can we increase the number of people who can effectively communicate with our children? (3) How can we encourage others to respect our children and feel more comfortable interacting with them? and (4) How can parents support and promote communication when personal time and energy are limited? For each of these questions, strategies for the home and community are offered separately. Examples of the suggestions include: (1) Encourage every family member to take responsibility for including and communicating with the child; (2) Network with the deaf community; (3) Model interactions with your child while in the community; (4) Expand the number of children you encourage to interact with your child; (5) Check senior programs, big brother/sister programs for possible communication partners; (7) Whenever possible, redirect family and friends to communicate directly with the child; (8) Promote awareness programs in the community; and (9) Pay attention to your child's mental and emotional health needs. (DB)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 465 236

COMMUNICATION AT HOME AND IN THE COMMUNITY

HELPFUL STRATEGIES & SUGGESTIONS FROM PARENTS & FAMILIES WITH A CHILD WHO IS DEAF-BLIND

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

From the 1999 National Parent Workshop sponsored by:

The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC)

The National Family Association for Deaf-Blind (NFADB)

IDEAs that Work
Office of Special Education Programs

BEST COPY AVAILABLE

ACKNOWLEDGMENTS

The contents of this document were drawn from over one hundred parents and family members of children who are deaf-blind who attended the 1999 NTAC/NFADB national parent workshop entitled "Important Practices in Communication: Making It Happen at Home and in the Community." It is their knowledge and experience that is reflected in these pages. A sincere thank you to all of the parent experts who attended the workshop and contributed to this "little book."

INTRODUCTION

In January 1998, the **National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC)** surveyed over 500 families of children who are deaf-blind to determine the most appropriate and meaningful topic for a national parent workshop. Results from this survey clearly indicated that communication was a critical issue.

During the summers of 1998 and 1999, NTAC and the **National Family Association of the Deaf-Blind (NFADB)** co-sponsored two national parent workshops with communication as the primary theme. For the first workshop, entitled "Going for the Best: Building Excellence and Strength Together," nearly one hundred parents from across the country were brought together in St. Louis, Missouri. These parents identified what they perceived to be the most important practices needed to effectively promote communication with their children who are deaf-blind. Their ideas were compiled in a booklet and distributed to families and professionals across the country.

The second workshop, "Important Practices in Effective Communication: Making it Happen at Home and in the Community," was attended by an even greater number of parents and family members. Participants worked together to identify strategies to put the practices identified in 1998 into action. The environments of home and community were targeted with regard to the following four questions:

- How can we facilitate and promote a child's individualized mode of communication?
- How can we increase the number of people who can effectively communicate with our children?
- How can we encourage others to respect our children and feel more comfortable interacting with them?
- How can parents support and promote communication when personal time and energy are limited?

Answers to these questions are contained within this little book. It is a wonderful collection of strategies, advice and suggestions from "parent experts."

How can we facilitate a child's individualized communication?

In the home

- Encourage every family member to take responsibility for including and communicating with your child

- Allow your child to have other, new communication partners - it will increase his or her skills and motivation

Attend workshops and conferences to learn about communication and deaf-blindness

Use a communication system that is sensitive to your family's needs

Try to be aware of natural opportunities to learn and to provide information and training

Allow wait time for your child to respond to you or to make a request

Being in close proximity to the child is usually required for effective communication

Establish regular routines for different activities to create common experiences to discuss with your child, e.g. weekly shopping trip

Create a sign or communication dictionary of the words and concepts your child uses

Use an experience book to promote conversation

Remember, conversations need a beginning, a middle and an end

Follow through with school instruction at home

Provide family sign language classes - use an Internet website to learn ASL (www.handspeak.com)

When talking to hearing persons in the presence of a child with deaf-blindness, remember to sign if the child uses sign

Sign stories to siblings, if your child uses sign language

If appropriate, use closed captioned TV

Network with the deaf community

Share resources such as web sites, CDs, and books with family members and friends

How can we facilitate a child's individualized communication?

In the community

- Model interactions with your child while in the community

Identify key people to inform and educate so they can help find opportunities for your child to communicate in other community settings (e.g. scout leader, your child's friends)

Tell people what your child's gestures (body language) mean so they can look for and understand your child's responses

Explain to people that they will need to give your child plenty of time to respond

Have a small communication dictionary available so that others can understand your child's communication system

Share sign language books with motivated and interested people

Check local programs that provide sensory activities, e.g., science museum, arboretum, etc.

- Provide sign language classes for care givers
- Be brief and be kind when in uncomfortable communication situations in the community
- Request Braille/picture menus in restaurants and provide community agencies with a list of restaurants that use them
- Encourage and reinforce the use of closed captioned TV and theater movies
- Advocate for sign language classes to be offered in the community for adults and children
- Explore interpreted plays in the community
- Use written notes to communicate when appropriate

How can we increase the number of people who can effectively communicate with our children?

In the home

- Expand the number of children you encourage to interact with your child - think of ways to teach them how to communicate with your child

Give yourself permission to let other people do some of the communicating

Begin small, with a circle of good communicators, then bring in more people

Teach immediate and extended family members about your child - let them know what your child likes to do, e.g. games, snacks, etc.

Encourage other family members to communicate by modeling how to do it

- At family meals, give others an opportunity to communicate with your child who is deaf-blind - leave the room - talk to your family about what happens when you do

Recognize that our kids are kids and they will interact with different family members in different ways - they will do different things for Dad or Grandma than they will do for Mom

Invite kids from the neighborhood who are near your child's age into your home! Make your home welcome and fun for others. Teach neighborhood children the best way to interact with your child

Increase opportunities for partial participation

Acknowledge the increased effort that is required of your child to participate in the family activities

Label items in your home environment with your child's favored communication (e.g., sign, symbols, words) so everyone can use the same language

Allow your child to engage in "typical" interactions in your house with siblings and their friends

Parent to parent networking can lead to playmate/companion connection

When siblings ask to help, allow them to help to the best of their abilities

Have easy access to sign language books

Use a communication book

Use games of all kinds to teach - siblings can be the teachers

Use homemade materials, such as a communication book or calendar box, to share information about your child's communication

How can we increase the number of people who can effectively communicate with our children?

In the community

Don't be an island -- others in the community may actually interact very well with our kids, which is not what we probably expect to happen

Continue your community involvement, e.g. church, library, shopping, recreation, and bring your child - introduce them to everyone - soothe over any awkwardness

When you notice other people's curiosity, offer information if they are interested - encourage interaction - other kids are often more open to these experiences than adults - they can become ambassadors for our kids, telling their parents about a new acquaintance

Give others an opportunity to volunteer to do things with your child

Use opportunities to demystify the differences between our children and others

Check into age appropriate community organizations and activities and give your child an opportunity to participate

Encourage school and other community resources to include your child in field trips and activities - help them understand how if they don't know

Frequent local merchants such as the hairdresser, gas station, bakery, convenience store - go to the same place on a regular basis - start doing this early in your child's life - repeated exposure is important

Provide information or in-service on your child's communication for church groups, bible schools

Join a playgroup in your area - establish peer connections by using a peer "social tutor" who could help increase relationships with other peers - this person could initially be paid but hopefully could be faded out

Check senior programs, big brother/sister program for possible communication partners

Model...model... model... good communication, e.g. touch cues, turn taking, correct social behavior

After modeling communication, suggest "you try" and step back and give others the opportunity - it's not about communicating perfectly but about making opportunities available

Have an intervenor with your child in the community

Think of different ways to explain your child's communication system to others - suggestions include: videotapes of your child, pictures of your child demonstrating signs he uses, homemade cards with key words and pictures, a communication dictionary

Recognize that not all people will respond well to your child and know that you don't owe everyone an explanation

How can we encourage others to respect our children and feel more comfortable interacting with them?

In the home

- Demonstrate pride in communicating with your child - be visible in doing this and your enthusiasm will rub off on others
- Whenever possible, redirect family and friends to communicate directly with your child
- Be open to visits from extended family - write a friendly note prior to the visit with suggestions for interacting and communicating with your child
- Motivate and empower family members to interact with your child - show them you are confident in their abilities
- Model and explain to all family members what your expectations are - involve family in developing teaching strategies
- Encourage family and friends to have physical contact with your child
- Find ways to demonstrate your child's abilities to help reduce other people's fear and awkwardness
- Make sure your child is an active, involved member of the family

Encourage family members to participate in your child's daily routine by pairing siblings to do chores - encourage your child's partial participation in the activities

Help your child be as self-sufficient as possible so others don't get upset or resentful that they have to help

Give responsibilities to your child that match his or her abilities and continually raise expectations

Be a normal family - demonstrate kindness - show respect

Talk about positive events, such as birthday parties and swimming, rather than negative events or problems all the time

Encourage spouse to spouse discussions of the issues

Advocate for more training for fathers and siblings - involve fathers and community members by giving up control (moms)

Accept negative attitudes from some family members if necessary, but continue to teach by example

How can we encourage others to respect our children and feel more comfortable interacting with them?

In the community

Take your child out! Be a part of the community - take risks - explore

Don't expect special treatment but look for ways to be involved

Aim high! Be proud of your child or family member

Present your child as a "kid" first - get to know other kids in the community and find ways to involve your child with them

Demonstrate patience so others see it and model it, as well - allow time for people to feel comfortable

Whenever possible, encourage people to talk directly to your child instead of talking about her while she is right there

Explain your child's abilities and needs to other parents so they can share information with their own children

Heighten awareness in public places - talk to people - teach one person at a time

Promote awareness programs in the community

Whenever possible, pick the same person to deal with at the store, restaurant, etc. - model communication with your child - step back and let them communicate

If someone is interested or curious, reach out to them, don't make them make the first move

Facilitate physical contact by explaining to others why touch is important for a person who doesn't see and hear

Start friendships at an early age - teach friends how to use your child's communication devices

Invite friends of siblings over so that the child can meet and interact with new friends - ask them "what's cool" - replace activities, clothes, etc. that are not age-appropriate

Publicly recognize the contributions of community members and supporters

Write stories of positive examples of community participation to share with other parents and community members

To the greatest extent possible, teach your child self-determination and self-advocacy so he can speak for himself

How can we support communication when time and energy is limited at home and in the community?

- Don't worry about teaching all the time - let home be different from school
- Pick your battles - set your priorities

Be aware of your child's energy level - determine his or her peak performance time of the day and focus attention and skill building activities for that time

Pay attention to your child's mental and emotional health needs

Be aware of sleeping patterns - make sure everyone is aware of medications and side effects

Anticipate and pay attention to stressful or potentially stressful situations

Infuse communication into everyday family life

Make it simple - when a lot is going on stay with the basics

Be consistent with cues and signs but allow for individual styles

Don't reinvent the wheel - seek information from professionals and other parents

Divide and delegate tasks among family members

Do pre-planning:

- ✓ have a printed list of your child's routine available for others
- ✓ have hearing aids and devices accessible and in working order
- ✓ pre-conference with doctors and medical staff to provide information and expectations for each appointment

Be aware of your own energy level:

- ✓ ask for help - seek respite - having a break is important
- ✓ accept appropriate help from others
- ✓ take care of your own physical & mental health
- ✓ exercise and play

Understand and protect your own and your family's boundaries

Don't try to be the "perfect" parent:

- ✓ be flexible
- ✓ compromise
- ✓ be able to say NO!
- ✓ give yourself time and space
- ✓ look at your daily schedule for ways to make it easier

Published by

NTAC

The National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind

To Contact NTAC staff:

Western Oregon University
Teaching Research Division
345 N. Monmouth Avenue
Monmouth, OR 97361
Voice: 503.838.8391
TTY: 503.838.9623
FAX: 503.838.8150

and

Helen Keller National Center
111 Middle Neck Road
Sands Point, NY 11050
Voice: 516.944.8900 ext. 311
TTY: 516.883.9059
FAX: 516.883.9060

E-mail: ntac@wou.edu
Website: http://www.tr.wou.edu/ntac/

To Contact NFADB staff:

National Family Association for Deaf-Blind
111 Middle Neck Road
Sands Point, NY 11050
Voice: 800.255.0411 x275
FAX: 516.883.9060
Website: http://www.cpd.usu.edu/nfadb/

Funded through grant number H025C60001 by the U.S. Department of Education, OSERS, Office of Special Education Programs. The opinions and policies expressed by this publication do not necessarily reflect those of NTAC or the U.S. Department of Education.